

**Michael and Margaret Bustell  
7 Highbrook Rd  
Norwalk, CT 06861**

March 16, 2009

Thomas P. Gaffey, Co-Chair  
Andrew M. Fleishmann, Co-Chair  
Education Committee  
Room 3100, Legislative Office Building  
Hartford, CT 06106

**Regarding: Raised Bill # 6666, Section 7**

**An act requiring School Districts to utilized Board Certified  
Behavior Analysts when an individual education plan includes  
applied behavior analytic services as part of a student's  
special education**

Madam Chair, Mr. Chairman and members of the committee:

My name is Margaret Bustell. I am a Norwalk Parent Leader and the parent of a child with autism. I am in **STRONG** support of Raised Bill # 6666, Section 7.

To illustrate the importance of this bill, I would like to share my personal story.

My son was diagnosed with PDD-NOS, a form of autism at 22 months. After developing normally for the first 15 months of his life, he had a severe reaction to his MMR vaccination and slipped away into autism. Our bright, talkative, happy little boy disappeared and left behind a silent, sullen, and disconnected child in his place. It was devastating.

My son's evaluation called for a minimum of 30 hours per week of Applied Behavioral Analysis (ABA) and he was assigned a provider through the Norwalk School District named Spectrum Kids. Unfortunately, this provider did not possess BCBA certification from the Behavior Analysts Certification Board. Had she had this certification, she would no doubt have been able to design an appropriate ABA program for our son. The sad fact is that she possessed virtually no qualifications at all.

Instead, she cobbled together a patchwork quilt of hodge-podge programs lifted from the internet and previous employers. Therapists were untrained and often left to interpret how a program should be administered. There was little customization towards the core deficits my son struggled with and little oversight of the execution of his program. Program books must be monitored weekly in order to capitalize on a child's success and advance him into new programs as

soon as he is ready. Without this skilled supervision, my son became quickly bored and uncooperative. We were losing valuable time.

Desperate to save our child, my husband and I enrolled our son in a private, intensive program led by experienced BCBAs. The new team was dismayed to review my son's program book and spent several months un-teaching him rigid, robotic habits he had learned from his previous provider.

Two weeks ago, after six months of working full-time with his new program, something clicked. My son is now speaking. In fact, he has spoken more in the past two weeks that he has in the past two years. I never thought I'd be able to say this, but I have actually lost count of how many words my child has.

The fact that my son is finally speaking now has much to do with the fact that he finally has an appropriate ABA program administered by Board Certified Behavioral Analysts in a **consistent** manner.

But how many other children in this state are languishing in ABA programs run by unqualified, un-certified instructors?

Members of the committee, the rates of autism are rising exponentially. However, with intensive, early intervention these children can make incredible gains and even recover. Passing Section 7 of Bill 6666 makes sense on all levels - morally, ethically and financially.

I urge you to protect the health and well being of Connecticut children.

**Please PASS Section 7 of Bill 6666.**

Thank you.

Best regards,

*Margaret Bustell*

**Svetlana Rodina-Brien**

**From:** Margaret Bustell [margaret.bustell@tns-global.com]

**Sent:** Thursday, March 12, 2009 12:09 PM


**To:** erikimmy@aol.com; kimhillgraham@sbcglobal.net; Maria.lacontino-Murphy@ubs.com; supukrish@yahoo.com; srodina-brien@pdcltd.com; Nancy L. Scimeca; jtjcv@optonline.net; Suzanne Letso; lauri.bretthauer

**Subject:** Another article on the Lore mess

Found this online today. It quotes some previous articles and speaks to the need to hire experts.

## Parents and school systems are vulnerable to autism quacks

March 11, 1:35 PM - Add a Comment

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Staff writer Lisa Chamoff reported in the Stamford Advocate that charges may be filed against Stacy Lore of Spectrum Kids of Carmel NY. Apparently Ms. Lore charged the town of Norwalk, Ct. close to \$170,000. for services rendered as an expert in autism therapy.

"Parents sounded the warning about Lore last year, and an attorney who investigated confirmed last month that Lore was not certified as a behavior analyst and did not have a doctoral degree as she claimed verbally and on invoices she sent to the district. Lore and several therapists she employed worked with eight Norwalk children in school and at home through August 2008."

This charge caught my attention as it reminds me about the vulnerability of parents of autism. We are the "deer in the headlights" following diagnosis. Then comes denial, followed by forge into action mode. I have always been a proponent of throwing enough "stuff" against the wall and something has to stick. That was my mantra regarding therapy. Speech, occupational, behavioral and play therapies encompassed our daily routine for years. Collectively, they are the life blood of behavioral intervention.

Regrettably, this news undermines the positive impact for hiring experts. Ideally, school districts should have enough trained staff to apply therapies. Sometimes outside experts are hired to train staff and para professionals. I never understood the historical divide between school staff and hired therapists. There is a prevailing attitude that rears its head at the PPT table. "Don't tell me my business" is sometimes evident in teachers and outside experts. My caveat has always been that the child is the fall guy when disputes arise.

Now that there is sufficient evidence that someone has lied about her credentials, it smacks of negative publicity. According to Fairfield Weekly.com "First, Stacy Lore created a company called "Spectrum Kids" with the declared mission to "meet the dynamic and ever-changing needs of children with Autism Spectrum Disorder and their families." Then, with the aplomb of modern day Pied Piper, she walked into the offices of Norwalk Public Schools with a résumé glowing with degrees and specialties: education, special education, psychology, applied behavior analysis programming, verbal behavior."

Clearly, Norwalk officials were duped by Ms. Lore, and their due diligence was remiss. However I do commend them for realizing that a behavioral approach planned by expert therapy is essential in helping children with autism. That thought process is pro-active and cutting edge. Sadly there are crooks in every business and this time disabled children were impacted by the crime.

**Margaret Bustell**

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## News

### Left Behind

A Norwalk Public School scandal shows that Connecticut has no idea how to teach children with autism

By Lauri Brett

Comments (3)

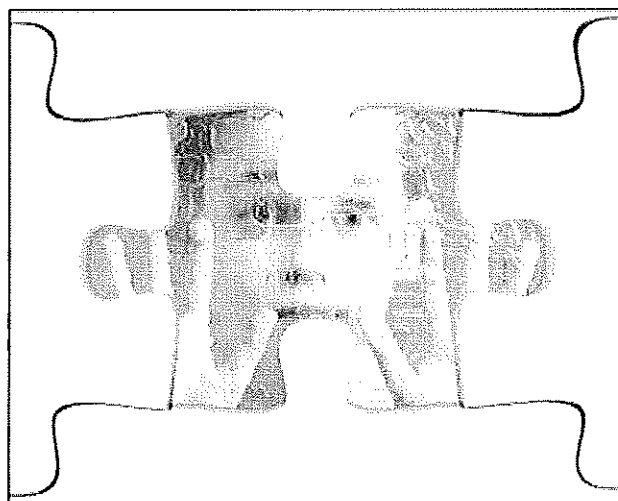
Thursday, November 20, 2008

First, Stacy Lore created a company called "Spectrum Kids" with the declared mission to "meet the dynamic and ever-changing needs of children with Autism Spectrum Disorder and their families." Then, with the aplomb of modern day Pied Piper, she walked into the offices of Norwalk Public Schools with a résumé glowing with degrees and specialties: education, special education, psychology, applied behavior analysis programming, verbal behavior.

Best of all, she was supposedly a Board Certified Behavior Analyst (BCBA), a coveted position awarded by the Florida-based Behavior Analyst Certification Board to those with at least a master's degree, 225 hours of graduate-level coursework, and field experience dealing with behavioral problems. BCBAs have to pass a grueling Behavior Analyst Certification Examination, and they are the only professionals entirely trusted to perform Applied Behavioral Analysis, an exact scientific method that is the preferred treatment of most autism organizations. Norwalk Public Schools hired Lore as a "Board Certified Behavior Analysis Consultant" and placed her in charge of programs for their learners with autism.

She allegedly referenced this alphabet soup of "qualifications" to convince area parents, desperate to help their children — afflicted with neuro-developmental disorders like autism, Asperger's syndrome and PDD-NOS (pervasive developmental disorder-not otherwise specified) — in and out of school. Lore charged per-hour rates of up to \$125 and fees for academic assessments of \$1,500. She even held charity fundraisers on behalf of her company, which is not registered as a nonprofit.

At first, Norwalk parents were excited the school had hired a BCBA to create programming for their kids, each of whom had behaviors that interfered with learning. A "Board Certified Behavior Analyst" would have been trained to perform full "behavioral autopsies" to root out the causes of problem behaviors. This is much better than the band-aid approaches less qualified professionals often provide.



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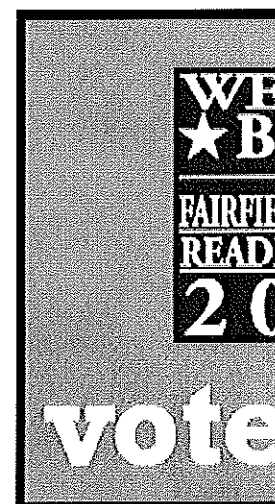
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### Public School Still Sucks

By FCW Editorial

03/12/2009

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The Internet star, potential Dodd challenger and talking head who was right elaborates on his philosophy

By Phil Maymin

03/12/2009

### Irony

By FCW Editorial

03/12/2009

### Back in Print

By Nick Keppler

"Now my four-year-old my son won't disrupt his class by loudly singing tunes he has heard on Nickelodeon," said a Norwalk parent, who asked to be referred to as "Nora." "He'll get a properly executed behavior plan."

"When the district hired Lore, she appeared to be an improvement upon what we'd had before," explained Norwalk parent Svetlana Rodina. "The school had sent someone without formal behavioral training to observe my four-year-old boy. In the parents' interview, we explained his sensory anxiety caused him to pull his clothes off on the playground. She joked, 'Maybe he's an exhibitionist.' We found that insulting, not funny."

Svetlana's hopes for improvement in the form of Stacy Lore rapidly dissolved with missed appointments from Spectrum Kids-hired professionals. "In December 2007, two therapists cancelled their appointments for the reason of non-payment," she says.

Svetlana reports that, after two years in a Norwalk Public School, her son's autism rating has risen, after he was re-evaluated by the New York-based McCarton Center.

Nora recounted the "cookie-cutter" home program provided by Lore's company. "When my three-year-old was being asked to say, 'A fork is an eating utensil,' he substituted a different word, like 'instrument.' It was marked incorrect, which meant he would be asked to repeat it next session. I feel it was those rote demands that caused his tantrums and other escape behaviors to increase rather than decrease."

Another parent, who asked to be called "Jill," reported that her Spectrum Kids-employed therapist had expressed alarm when her boss began driving a new Mercedes while her own paycheck had bounced.

When contacted for this article, a former therapist for Spectrum Kids — who, for fear of her future in the field, asked that her name not be used — detailed being sent by Lore into a Planning and Placement Team meeting unprepared, having been on the job for only a week. Parents of kids with autism know how vital a PPT is; they prepare for it for months. It's the meeting where parents, doctors, educators and school administrators create an Individual Educational Plan (IEP), a legally binding contract outlining what the child needs and what the school district will provide. A therapist showing up unprepared is like a lawyer showing up to a trial without a briefcase.

Though parents began sending concerned e-mails to Norwalk Public Schools in March, Lore's bogus competency completely unraveled in August, when they compared notes during a monthly Autism Parents' Support Group meeting.

The parents decided a background check was in order. They began checking those glowing credentials, calling the universities at which Lore claimed to hold degrees. Though it's possible she may have had some of the past employment and training she claimed to have had, the parents have been unable to substantiate a Magna Cum Laude New York University Masters Degree in Clinical Psychology — or any New York University enrollment, even though her résumé boasted a New York University Ph.D. in "Behavior Analysis." They also could not confirm a New York State Teacher's Certification. The Behavior Analyst Certification Board, meanwhile, confirmed that Lore does not have BCBA certification.

03/12/2009

**Fate of the Arts**

By Sean Corbett

03/12/2009

**Ferret War**

By Nick Keppler

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**Gary Is Facebooking on the Job**

Why tweeting lawmakers are good for democracy

By Andy Bromage

03/12/2009

**Eternity Leave**

Legions of laid-off scribblers turn the experience of getting canned into fodder for novels, self-help books and documentaries

By Brianna Snyder

03/12/2009

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Spectrum Kids is now out of business, and in August, Lore lost her contract with Norwalk Public Schools. In early November, parents began presenting their pleas for accountability before the Board of Education at its bi-weekly meetings. The Board is gathering a report for December and they has yet to make a public statement on the fiasco, though the district's human resource office told the *Norwalk Hour*, "The Norwalk Public Schools is not in possession of any documents regarding the education and credentials of Stacy Lore."

"I've given up on the system," cried Svetlana Rodina before the Board of Ed.

"I have since learned from experts that Lore's hack behavioral programming did my child more harm than good," claimed Nora. "Lore's interventions elicited robotic, rather than flexible, responses in his learning behaviors." Nora is in the process of recovering nearly 100 lost public school service hours from Norwalk's public school system. "How can they not have checked those credentials?" she asked with tears.

Jill sought an independent evaluation of Lore's plans from a recently opened private autism school. The school's programming director declared, "This book contains no programs to address the core deficits of autism."

After substantial parent outcry, Attorney General Richard Blumenthal began investigating Lore, claiming that, by misrepresenting herself, she may have violated consumer protections laws. The school district has not yet responded to record requests despite a complaint filed by the parents and State Sen. Bob Duff (Darien, Norwalk) with the Freedom of Information Commission in Hartford.

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"More children may be harmed," worries Norwalk mother Josephine Tirado, who learned about Lore at the monthly Autism Parents' Support Group. "We do not really know how many towns or families were working with Ms. Lore, or whether other school districts are still being charged large sums of money for services she is actually not qualified to provide."

This is not the only instance of someone falsely claiming expertise to help children with autism. In Ocean County, N.J., Nancie Fisher was sentenced last year to three years in prison for a similar offense.

Although parents have appeared in tears at Board of Education meetings, holding pictures of their children, many declined to be named for this article. "I have a PPT coming up. I don't dare say anything," said one parent. "My child has to have the services. I can't afford to be seen as a troublemaker." Every intervention/education hour is precious in the life of a child with autism.

"The school did not have a trained paraprofessional for my son when Spectrum Kids stopped providing their consulting," said "Constance." "So he had to stay home for several weeks."

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Autism is growing at epidemic proportions, faster than any other learning disability in the United States. 224,594 cases in people ages six to 22 were known in 2006, compared to 34,375 cases in 1996, according to the Centers for Disease Control and Prevention.

Hope for recovery currently resides at uncharted crossroads of science, medicine and education, leaving the door wide open for many to lay claim to cures. A complicated neurological disorder for which no single methodology achieves full recovery, a myriad of alternative therapies, as well as established ones, are often sought in combination.

Hollywood actress Jenny McCarthy has been highly profiled in the media in her struggle to help her son with autism through the proven method of Applied Behavior Analysis, but also in a less proven "alternative" area of biomedical intervention. McCarthy has declared her child is "in recovery," and she is advocating the "alternative" treatments that she says helped him.

A film titled *Finding the Words*, produced by the mother of a child with autism, documents the broad range of doctor, therapist and parent intervention efforts throughout the country, with many reporting positive outcomes. "Never give up hope," cries one of the parents interviewed in the film, whose child achieved extraordinary progress.

No wonder parents and service providers get a little confused about what "works." Lois Rosenwald, founder and executive director of the Connecticut Autism Spectrum Resource Center in Niantic, says, "In my years in this agency, I have seen parents whose I'll-try-anything approach is alarming by any standards."

Yet, there is one commonly agreed-upon form of treatment, Applied Behavioral Analysis, the only evidence-based approach proven effective in educating those with autism. The U.S. Surgeon General and the New York State Department of Health have endorsed it, and some insurance companies have recognized it as a necessary treatment. In July 2007, its use was endorsed in a Department of Defense report on services provided to the children of military personnel.

ABA is a complicated science that educators begin to learn at the Masters level. In simple terms, it is the study of the causes of human behavior. In the case of children with autism, it's a study of what triggers cause the troubling behavior. Once those root causes have been identified, these triggers are lessened or taken away as part of a plan that is shared with *everyone* involved in the child's development.

It is commonly agreed that, at this point, only a Board Certified Behavioral Analyst (BCBA) can perform ABA. (A BaCBAs, or a Board Certified *Associate* Behavior Analyst, is the second-tier accredited position the Behavior Analyst Certification Board offers and is qualified to perform many aspects of ABA.) ABA practiced by anyone else, many agree, is like surgery done by someone who's not a licensed surgeon — it's not only usual unhelpful, it can often be harmful.

But with autism now striking one in 150 children, well-intentioned schools struggle to cope with this influx at the local level, wanting to provide whatever treatment closest to ABA seems doable.

"Many parents and school districts are still unaware of what kind of education and experience someone identifying themselves as a behavior analyst should have," says Suzanne Letso, a parent of an adolescent with autism and the executive director of the Connecticut Center for Child

Development, a private school for the autistic.

"ABA-like' is not Applied Behavior Analysis," says Lawrence Berliner, a Hartford-based special education lawyer with the firm Klebanoff and Alfano. "I know some school districts have adopted that approach, as well as disputing whether ABA is even an educational service that has to be included in an Individual Educational Plan. Consequently, some parents have been forced to secure appropriate services privately or settle for a less than appropriate IEP."

Parents are demanding analysts in public schools, and schools want them. But children with autism can become sacrificial lambs to would-be specialists—even some who are well-intentioned or have certifications in related fields.

Lois Rosenwald, of the CT Autism Spectrum Resource Center, says, "Districts are just not educated enough around this diagnosis. A lack of national and state standards absolutely allows something like [the Norwalk case] to occur. I would suspect this has happened before, but we just haven't heard of it."

Originating in 1975 and amended in 1997, a special education law known as the Individuals with Disabilities Act requires school systems to provide both a free and "appropriate" public education to disabled students, individually tailoring their programs as needed.

"It's the word 'appropriate' that we are always arguing," says Berliner. A patchwork quilt of service exists — all in order to reach a vaguely defined level of quality called "appropriate."

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The case unveils a complicated set of dynamics whereby the State of Connecticut is not only leaving children with autism and related syndromes behind, but throwing them off the bus. ABA is not required for the education of autistic kids by state law and BCBAs are not, by law, the only professionals who can do something like ABA.

Connecticut education law (Sec. 10-222c) requires a "documented good faith effort" to obtain information relevant to a person's fitness for employment, but a definition of what constitutes "adequate credentials" for teaching individuals with autism remains elusive in the state. It is not that surprising that Stacy Lore, creator of the Spectrum Kids therapy company with a license originating in Texas, could supply Norwalk Public Schools with a convincing packet of credentials and be contracted by the district.

"School administrators must have not wanted to look a gift horse in the mouth," says Constance.

House Bill 5590 was signed into law in June, 2008. It requires recommendations for a new state plan for instructors of students with autism and other developmental disabilities, to be reported to the General Assembly in February 2009.

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"Even while facilitated discussions are taking place, a clear definition of the required elements and procedures of an autism education program is necessary before programs of individual districts can



even be measured for their suitability and effectiveness," says Beth Lambert, president of CT FEAT (Families for Effective Autism Treatment).

Letso, of the Connecticut Center for Child Development, is an advocate for state regulation of people who can perform ABA. "Proof of certification would be required if the state recognized behavior analysts as 'related service providers,'" she argues.

"Related service providers," under state law, are school personnel like speech therapists and nurses, and they must provide some accreditation. Many people put in a position to work with kids with autism are not considered "related service providers"—even those put in charge of treatment, as Stacy Lore was.

And one need not directly lie about BCBA accreditation to promise goods they can't deliver. Without specifications set forth at the state level, a person without a BCBA will describe themselves as a "behavior analyst," because they are analyzing behavior based on what they've learned, even if they haven't had the required education for a science as delicate as ABA.

Into whose pockets will we reach for these on-staff Board Certified Behavior Analysts? Throughout the country, limited resources and growing demand leave educators and parents grappling with questions like, "What are [Autism Spectrum Disorder] children entitled to? Who should pay?" according to a recent article in *The Education Digest* ("Reaching and Teaching Autistic Kids").

The problem in Connecticut is confounded by the inadequacy of state university programs that offer programs in the field of autism. Beth Lambert, of CT FEAT, declares, "Within our state, there is no backbone for a behavioral program in autism. Because we cannot rely upon our state's resources, at present all BCBAs must be attracted from other areas."

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In Stamford, one frustrated parent sought an out-of-state private school to shed light on the autism programming in her school district. Robin Portanova created a "wish list" of needs she felt were not being addressed. Among those were "life skills for daily living that could foster independence, social skills, training to all involved with our children, parent and mainstream teachers training, and a BCBA on board."

Portanova discovered Gersh Academy, an institution founded in Melville, N.Y. Gersh's commitment to individuals with autism extended from pre-school to college. She brought her "wish list" to Wayne Holland, Stamford Public School's director of special education, and Karen Poggi, director of Autism Spectrum Disorder Services. They agreed to request an assessment by Gersh Academy professionals. For two years in a row, Gersh has won the ability to provide service in Stamford after a competitive bid process.

Though Stamford parents were thrilled Gersh would begin providing programming at the start of the fiscal year, they had the rest of the year to get through. "After the mid-year needs assessment, we kept hearing, 'There's not enough money in the budget to start these services right away,'" recalls Portanova. "At one point, I stood up in a meeting and announced, 'Yes, the budget is tight. I don't want to hear about money. I'm going to start a non-profit organization to raise money for our children's' needs.'"

In January 2007, Portanova founded Stamford Education for Autism (SE4A) with three other Stamford parents. The organization funded the district's Gersh-recommended services until the end of that school year. She began developing fundraising events, such as a recent Roberta Flack concert. Since its inception, the organization has raised at least \$40,000.

"It was a dream come true for me when they agreed to come to Stamford," said Portanova. "Everything they offer is so topnotch. It's a dream come true for our community. It's like 'Wow, our kids can succeed.'"

## Comments (3)

✶Post a Comment

Do not forget the education of the grown children with autism -- the "adults" in the eyes of the law. The child with classic autism is left without autism supports when school ends at age 21. FAP - CT Friends of Autistic People -allied with Stamford E4Autism.-- educates parents and the public about the needs of the adult child and advocates with the legislators to create a mandate for the children who are aging out .

FAP also plans a farm academy where the children can continue to learn what they need for life - acadmic, social and voational skills as a continuation of the IDEA program on a "adult" basis. As is usually the case , your article also left out the grown child with autism and did not inquire wwhat happens to hi 203-661-8510 to get involved in with the legislators and athier shool barea iiii

Posted by brita Darany von Regensburg on 11.18.08 at 20.19

Dear Lauri,

Excellent article and very concerning to professionals like myself who work with children with developmental disorders. One quick correction there is a advanced psychology organization by the name of the American Board of Professional Psychology (ABPP) which provides board certification in cognitive-behavioral psychology including ABA techniques.

Sincerely, Michael S. Cohen, Ph.D., ABPP-Rehabilitation

Posted by Michael S. Cohen, Ph.D., ABPP on 11.20.08 at 11.44

This is such a shame, and as a BCBA who was swindled by Nancie Fisher, I believe it is of the highest importance to check a person's credentials. I learned this lesson too late, and my family was almost homeless because I trusted someone instead of double checking credentials. Parents, ask for proof of certification, and school should do no less. My heart goes out to those parents and professionals who have been taken advantage of.

remember, you can check someone's certification on the BACB website! At the very least, do that.

Dana Garner, BCBA

Posted by Dana on 2.1.09 at 18.46

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